

# Publication Report



## Childhood Cancers in Scotland (1983-2007)

Publication date – 29 March 2011

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## About ISD

Scotland has some of the best health service data in the world combining high quality, consistency, national coverage and the ability to link data to allow patient based analysis and follow up.

Information Services Division (ISD) is a business operating unit of NHS National Services Scotland and has been in existence for over 40 years. We are an essential support service to NHSScotland and the Scottish Government and others, responsive to the needs of NHSScotland as the delivery of health and social care evolves.

**Purpose:** To deliver effective national and specialist intelligence services to improve the health and wellbeing of people in Scotland.

**Mission:** Better Information, Better Decisions, Better Health

**Vision:** To be a valued partner in improving health and wellbeing in Scotland by providing a world class intelligence service.

## Official Statistics

Information Services Division (ISD) is the principal and authoritative source of statistics on health and care services in Scotland. ISD is designated by legislation as a producer of 'Official Statistics'. Our official statistics publications are produced to a high professional standard and comply with the Code of Practice for Official Statistics. The Code of Practice is produced and monitored by the UK Statistics Authority which is independent of Government. Under the Code of Practice, the format, content and timing of statistics publications are the responsibility of professional staff working within ISD.

ISD's statistical publications are currently classified as one of the following:

- National Statistics (ie assessed by the UK Statistics Authority as complying with the Code of Practice)
- National Statistics (ie legacy, still to be assessed by the UK Statistics Authority)
- Official Statistics (ie still to be assessed by the UK Statistics Authority)
- other (not Official Statistics)

Further information on ISD's statistics, including compliance with the Code of Practice for Official Statistics, and on the UK Statistics Authority, is available on the [ISD website](#).

## Introduction

The Scottish Cancer Registry publications include data on cancer at all ages, but the classification used is more suited to adult cancers than those found in persons under 15 years of age, whose cancers are more appropriately classified by histology than anatomical site. The data provided in the annual publications for incidence, mortality and survival from cancer at this age group have been re-analysed in accordance with the internationally accepted childhood cancer classification system.

The information provided by these reports are used by the Scottish Government, NHS Boards and cancer charities to understand and plan cancer service requirements for persons in this age group.

## Key points

- In the period 1983-2007, there were 3,235 children under the age of 15 diagnosed with some form of cancer, representing an average of 130 cases per year and less than 1% of all cancers diagnosed in Scotland each year, with a general increase over time.
- In the same period, 815 children died of cancer, with a general (but not statistically significant) decrease in mortality from childhood cancer over the time period.
- Survival from childhood cancers has generally increased over the 25 year period in all follow-up intervals analysed (1, 2, 3, 5 and 10 years after diagnosis).

## Results and Commentary

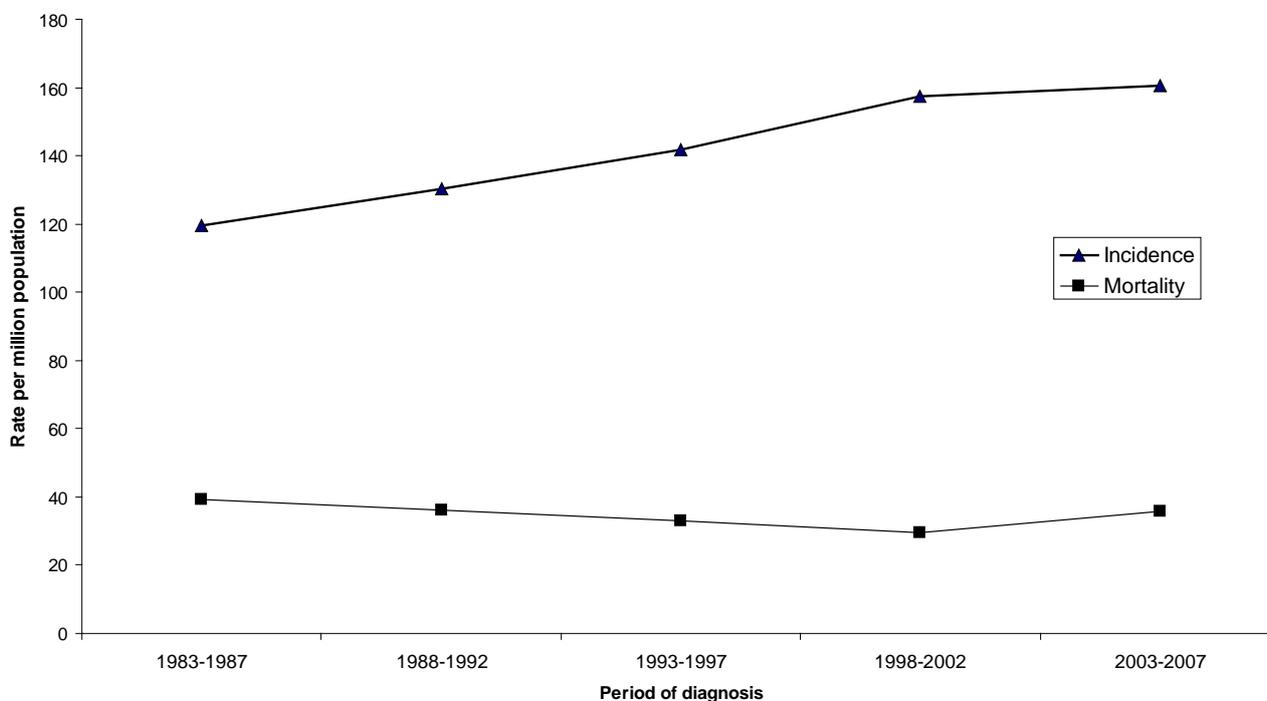
The Scottish Cancer Registry regularly publishes data on cancer at all ages, but the classification used (the International Classification of Diseases) is more suited to adult than childhood cancers. Adult cancers are classified primarily by anatomical site of origin, whereas cancers in young people are, in general, more appropriately classified by tumour type (histology). To address this issue, separate analyses of the patterns of childhood cancer incidence, mortality and survival are published by the ISD Cancer Information Programme using more appropriate classifications of the disease. In this report, childhood cancers diagnosed in Scotland between 1983 and 2007 are described using the [International Classification of Childhood Cancer \(ICCC, Third Edition\)](#), as implemented by [SEER \(USA\)](#). Note that the ICCC includes some disease entities that would be classified as neoplasms of uncertain or unknown behaviour, or benign neoplasms in the International Classification of Diseases (ICD). For this reason, there may be small differences in numbers of cases, deaths, and survival estimates, depending on which classification is applied.

### Incidence

In the 25 year period 1983-2007, a total of 3,235 children under the age of 15 were diagnosed with some form of cancer, as defined by ICCC-3 (1792 boys, 1443 girls), an average of approximately 130 cancer diagnoses per year ([Table 1](#)). Cancers in this age group represented less than 1% of all cancers diagnosed in Scotland in 2007.

Childhood cancers have increased in incidence between 1983 and 2007 (Figure 1), from an age-standardised rate of 120 cases per million population in the period 1983-1987 to 161 cases per million in the period 2003-2007. Age-standardised rates permit comparisons over time whilst taking into account changes in the underlying population structure, an important consideration because there have been changes in the relative proportions of different age groups in the Scottish population between 1983 and 2007 (Figure 2). Part of the observed increase in incidence may reflect improvements in data quality, changes in the classification of disease over time, and the fact that 'benign' tumours of the brain and central nervous system (CNS) have only been collected by the Scottish Cancer Registry since the year 2000.

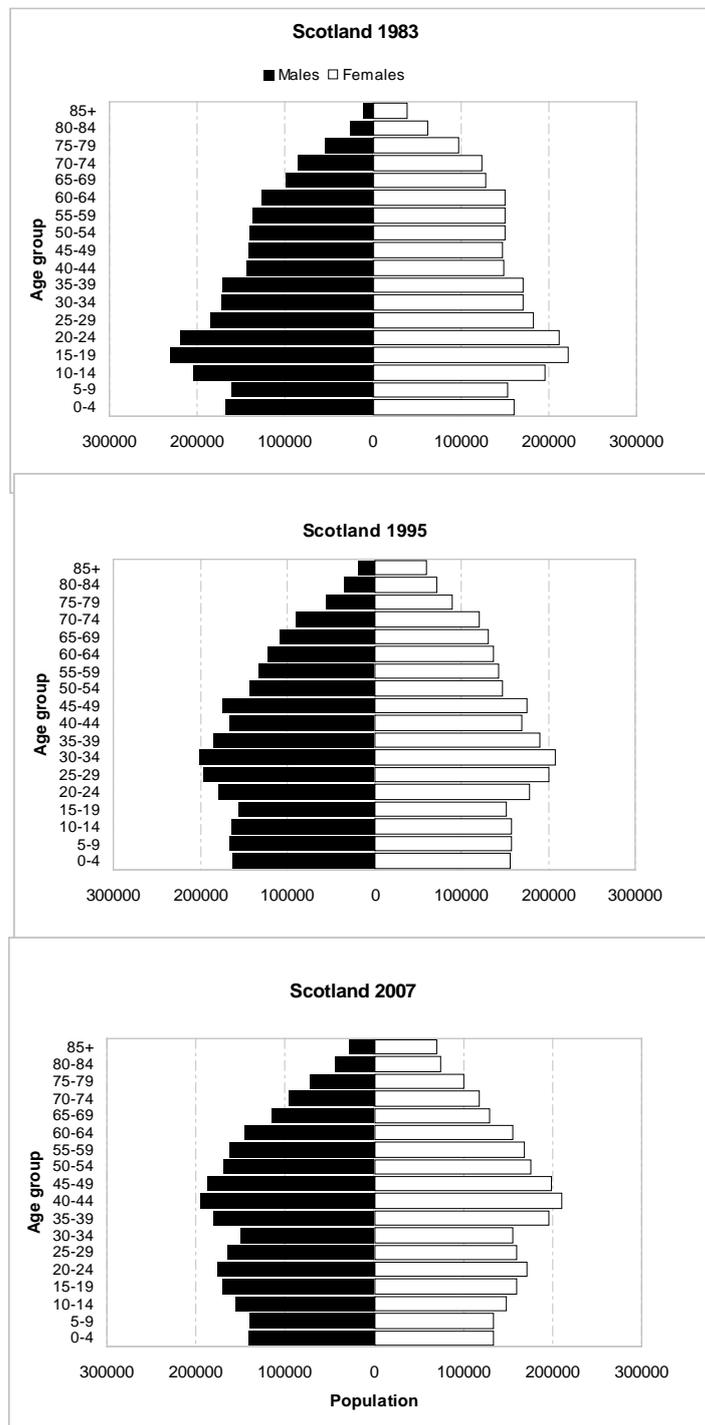
**Figure 1.** Trends in age-standardised incidence and mortality rates of childhood cancers per million population



Source: Scottish Cancer Registry, ISD (registrations); General Register Office for Scotland (deaths)

Of the individual cancer groupings, the most frequently occurring childhood cancer in both sexes is that of the grouping of leukaemias, myeloproliferative and myelodysplastic diseases, comprising approximately one third of all of the registrations ([Table 1](#)).

**Figure 2. Population age structures in Scotland: 1983, 1995, 2007**



Source: General Register Office for Scotland

## Mortality

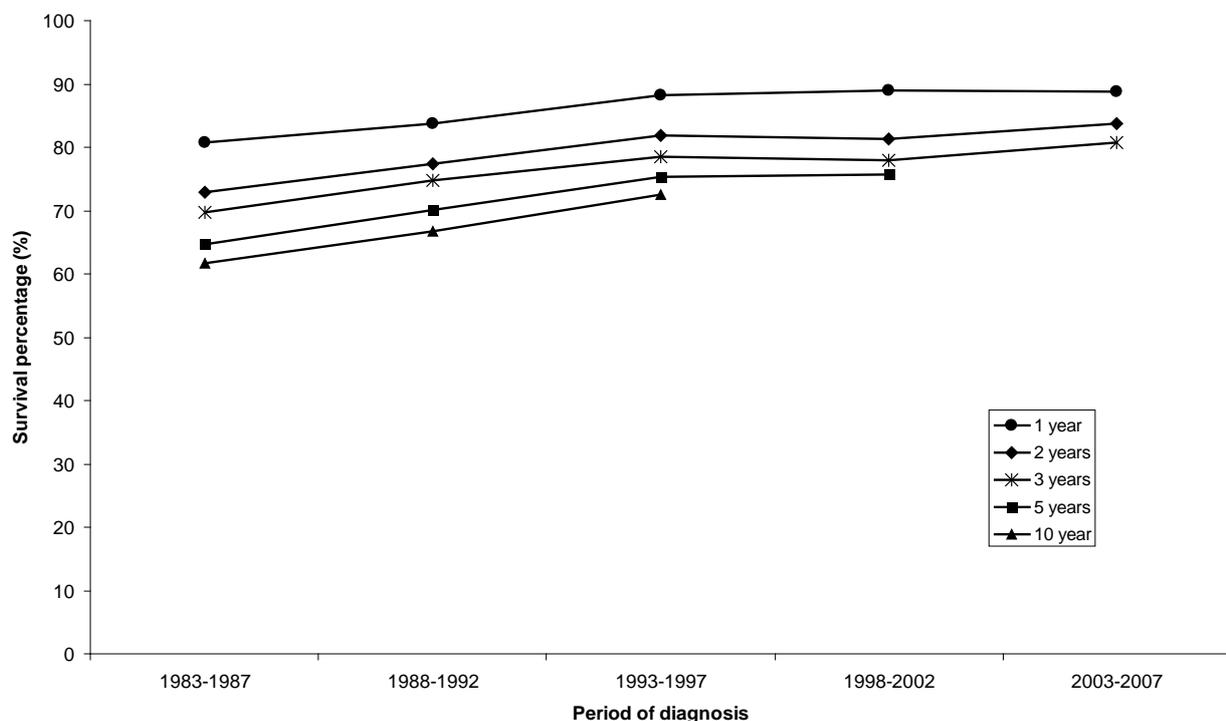
In the 25 year period 1983-2007, 815 children under the age of 15 died of cancer: 458 males and 357 females ([Table 2](#)). Among all children dying from cancer, approximately one-third of the deaths were due to CNS and other intracranial and intraspinal tumours, with almost another third due to leukaemia.

There was a general decrease in mortality from childhood cancer in the period 1983-2007, from just over 39 deaths per million population in 1983-1987, to just over 36 deaths per million population in the period 2003-2007 ([Figure 1](#)). The trend is not statistically significant as there is considerable variation over the 25 year period.

## Survival

Overall, there was an increase in observed survival from childhood cancer over the 25 year period 1983-2007 ([Figure 3](#)), in all of the follow-up intervals analysed (1, 2, 3, 5 and 10 years). However, observed survival for females shows a non-significant decrease in the most recent time period, 2003-2007 ([Table 3](#)). Fluctuations in survival estimates are likely to be explained, at least in part, by random variation due to small numbers of cases and deaths.

**Figure 3. Trends in survival from childhood cancers (all cancers combined) by age group, sex and period of diagnosis**



Source: Scottish Cancer Registry (registrations); General Register Office for Scotland (deaths)

## Glossary

neoplasm

cancer

## List of Tables and Figures

No.	Name	Time period	File & size
Table 1	<a href="#">Childhood cancer incidence</a>	1983-2007	Excel [34kb]
Table 2	<a href="#">Childhood cancer mortality</a>	1983-2007	Excel [61kb]
Table 3	<a href="#">Childhood cancer observed survival</a>	1983-2007	Excel [20kb]
Figure 1	<a href="#">Trends in childhood cancer incidence and mortality</a>	1983-2007	Excel [52kb]
Figure 2	<a href="#">Scotland population structures 1983, 1996, 2007</a>	1983-2007	Excel [66kb]
Figure 3	<a href="#">Trends in childhood cancer survival</a>	1983-2007	Excel [50kb]

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## Further Information

Further information on Child Health in Scotland can be found on the [Child Health webpages](#) of ISD Scotland.

Further information on cancer statistics can be found on the [Cancer Information Programme website](#).

For information on other health topics, please see the [ISD website](#).

## Appendix

### A1 – Background Information

1. Results are presented for cases diagnosed between 1983 and 2007 for the 12 main categories of childhood cancers, for an analysis covering a 25 year period. Note that the follow-up period for survival analyses was to 31 December 2008.
2. The classification system used for childhood cancers is the International Classification of Childhood Cancer (ICCC, Third Edition), as implemented by SEER (USA) and detailed here: <http://seer.cancer.gov/iccc/iccc3.html>. Adult cancers are classified using the International Classification of Diseases (ICD, Tenth Edition).
3. Mid-year population estimates used for calculating the rate per million population were supplied by GROS and are published on their website at [www.gro-scotland.gov.uk/statistics/theme/population/estimates/index.html](http://www.gro-scotland.gov.uk/statistics/theme/population/estimates/index.html) (last accessed 14 December 2010).
4. Because of the small number of registrations and deaths many of the trends and differences amongst groups must be interpreted with caution, as even small absolute changes can introduce large percentage differences.

## A2 – Publication Metadata (including revisions details)

Metadata Indicator	Description
Publication title	Childhood Cancers in Scotland
Description	Enumerating incidence, mortality and survival of cancers in persons aged under 15 years in Scotland in the years 1983-2007, using the International Classification of Childhood Cancers.
Theme	Health and Social Care
Topic	Conditions and Diseases
Format	PDF report
Data source(s)	Scottish Cancer Registry (SMR06), General Register Office for Scotland
Date that data was acquired	November 2009
Release date	29 March 2011
Frequency	Occasional
Timeframe of data and timeliness	A 25 year period was desirable for the analysis and extracted to give most recent data available at the time of extraction. Completion of the analysis was delayed as a result of analyst availability.
Continuity of data	Previous Childhood Cancer reports used the first edition of the ICCC; this uses the third edition. There may be some artefactual differences in trends as a result.
Revisions statement	As with other population-based cancer registries, the Scottish Cancer Registry is dynamic, with ongoing updating of records. Each year's release includes a refresh of the previous years, and as new registrations from previous years come to light, or changes in the coding are taken into account, the numbers may change. The timing of the release is intended to balance the likelihood of significant revision with timeousness of data.
Concepts and definitions	<a href="#">Cancer Information FAQs</a>
Relevance and key uses of the statistics	Number of cases, mortality rates and survival allow the Scottish Government to plan for provision of cancer diagnosis and treatment services, and palliative care for the under 15 year olds.
Accuracy	Registry data are subject to validation at data entry and quality assurance procedures. See the <a href="#">Cancer Information FAQs</a>  For coding of deaths: <a href="http://www.gro-scotland.gov.uk/statistics/deaths/death-certificates-and-coding-the-causes-of-death/index.html">http://www.gro-scotland.gov.uk/statistics/deaths/death-certificates-and-coding-the-causes-of-death/index.html</a>  Reported data are compared to previous years' figures and to expected trends.
Completeness	At time of extraction, data for the most recent year are estimated to be at least 98% complete. See above note on Revisions. Routine indicators of data

	quality are compared to the rest of the UK and to other countries, and are available at <a href="http://www.ukacr.org">www.ukacr.org</a> . There have been adhoc studies of data completeness in the past. See the <a href="#">Cancer Information FAQs</a>
Comparability	Cancer incidence data are regularly compared with the UK and other countries, for example in the publication <a href="#">Cancer Incidence in Five Continents</a> . Cancer mortality data are regularly compared with other UK countries and the UK as a whole (eg NCIS) and international reports (eg EUROCIM). In such comparisons, data are provided only at national (Scotland) level.
Accessibility	It is the policy of ISD Scotland to make its web sites and products accessible according to published guidelines. For further details <a href="#">go to our accessibility page</a> .
Coherence and clarity	The report is available as a .pdf file with embedded tables and charts.
Value type and unit of measure	Numbers of cases and deaths, rates of cases and deaths as crude and age and sex standardised rates. Survival expressed as percentages.
Disclosure	The <a href="#">ISD protocol on Statistical Disclosure Protocol</a> is followed. For this publication, at the levels of aggregation presented, the risk of disclosure was assessed as being low risk and so no further statistical disclosure control methods were employed.
Official Statistics designation	Official Statistics
UK Statistics Authority Assessment	Not applicable
Help email	<a href="mailto:nss.isdcancerstats@nhs.net">mailto:nss.isdcancerstats@nhs.net</a>
Date form completed	11 April 2011

## **A3 – Early Access details (including Pre-Release Access)**

### **Pre-Release Access**

Under terms of the "Pre-Release Access to Official Statistics (Scotland) Order 2008", ISD are obliged to publish information on those receiving Pre-Release Access ("Pre-Release Access" refers to statistics in their final form prior to publication). The standard maximum Pre-Release Access is five working days. Shown below are details of those receiving standard Pre-Release Access and, separately, those receiving extended Pre-Release Access.

Standard Pre-Release Access:  
Scottish Government Health Department  
NHS Board Chief Executives  
NHS Board Communication leads

### **Extended Pre-Release Access**

This extended Pre-Release Access is given to a small number of named individuals in the Scottish Government Health Department (Analytical Services Division). This Pre-Release Access is for the sole purpose of enabling that department to gain an understanding of the statistics prior to briefing others in Scottish Government (during the period of standard Pre-Release Access).

Scottish Government Health Department (Analytical Services Division)